

## **Lorri Unumb**

### **Senior Policy Analyst and Counsel – Autism Speaks**

Parent of a 8-year-old son with autism

Attorney: Senior Litigation Counsel with United States Department of Justice  
Law Professor at George Washington University Law School

Autism is a medical condition, brought on through no fault of family. Diagnosed by a medical doctor. Treatment prescribed by medical doctor.

“Autism” is actually an imprecise term: some people use it interchangeably with “autism spectrum disorder” and others use it to mean one of the ASDs. In fact, there are three distinct diagnoses within the family of autism spectrum disorders. (See chart.) The umbrella diagnostic category is called Pervasive Developmental Disorder. Within that umbrella category are 3 conditions known as ASDs: Autistic Disorder (or “classic autism”), Asperger’s Syndrome, and PDD-NOS. Across the spectrum, people vary greatly in terms of type and severity of deficits. Interestingly, 4 times more common in boys than in girls.

Although there is no known cure for autism, it can be treated so that the symptoms are not disabling. A non-verbal child can gain the ability to communicate; a non-social child can gain interaction skills. So, while they’re not cured, they can overcome the disabling aspects of the condition.

The most commonly-prescribed treatment protocol involves a therapy called “Applied Behavior Analysis,” or ABA. This is a therapy that has been used for many decades to treat autism, and yet the insurance industry continues to deny coverage for ABA therapy, often on the basis that it is “experimental.” That self-serving conclusion is simply not supported by the science, and the Surgeon General, the National Research Council, and the AAP all have endorsed ABA. (Show sample coverage positions, which show blanket exclusion of ABA therapy.)

Studies show that, if ABA therapy is administered intensively and by properly-trained therapists, approximately half of the treated kids will “overcome” their autistic characteristics to such an extent that they can enter 1<sup>st</sup> grade indistinguishable from their peers. And the other half make significant gains, too, such that they need less support for the rest of their lives. (Lovaas, UCLA 1987)

As I mentioned, though, ABA must be administered intensively, often 40 hours/week. And this, of course, makes it expensive. My own son’s autism is very severe, and his therapy has cost us, out-of-pocket \$75,000 per year. (Because of this extraordinary medical expenses, we’ve been audited on our taxes 3 times.) Most kids don’t require anything close to this much therapy, but the few, truly severe kids do. Fortunately, my husband and I are blessed with good jobs, and we were able to sacrifice to afford the therapy for our son. But how many Michigan families do you know that have that kind of money to sacrifice? Or even half that much? Most don’t, and most of those children are going untreated. It’s sad that in the USA, we know of a treatment that works, and yet we have kids who can’t get the treatment they need because their parents aren’t wealthy. And it’s not only sad; it’s unfair, given that these families are paying premiums every month to cover their kids. These are families who are doing the right thing, by buying insurance for their families to insure against exactly this kind of unforeseen & unprovoked medical disaster.

A 2006 study from the Harvard School of Public Health found that if a child with autism is not properly treated, the societal cost for that one child over their lifetime is \$3.2 million. (Ganz 2006). In addition, a 1998 study for the state of Pennsylvania projected an actual cost savings to the state of over a million dollars per child. (Jacobson, Green 1998). Do the math: 1 in 150 Michigan kids diagnosed; only the wealthy few get treatment; and multiply each remaining child by over a million dollars. That’s how much Michigan taxpayers will shell out if these kids don’t get treatment. Lest

you think, “We’ll just handle these people in our budget the same way we’ve always handled it, think again. Just 15 years ago, the prevalence rate of autism was 2-5 per 10,000. Today, it is 1 in 150. Scientists don’t know the reason for the increase, but we all understand the ramifications. There’s a huge autism tsunami coming, and it is going to cost the state an extraordinary amount of money in special education and adult care if the current generation of kids does not get the treatment they need. Without private insurance playing its part, the treatment is simply not going to happen.

Faced with this reality, other states – 13, to be specific – now require insurers to play their part. (See chart). Twelve states have passed this legislation, or something very similar, in the past 2 years:

South Carolina (2007)	Arizona (2008)	New Mexico (2009)
Texas (2007)	Louisiana (2008)	Montana (2009)
	Pennsylvania (2008)	Nevada (2009)
	Florida (2008)	Colorado (effective today)
	Illinois (2008)	Connecticut (pending sig.)

Indiana passed a similar bill 8 years ago – in 2001 – the same year the Attorney General in Minnesota entered into a settlement agreement with that state’s major insurer (BCBS) to require coverage for autism, including coverage of Applied Behavior Analysis therapy. And many other states are considering similar legislation right now.

One of the reasons I’m here today is because I worked on the legislation in South Carolina that started the recent movement toward coverage, and I’ve seen it successfully implemented. Children who have never before been able to receive treatment are making remarkable progress. Providers have joined adequate networks of participating providers and negotiated satisfactory reimbursement rates. And I can tell you, despite the doomsday predictions from opponents that we’ve heard in state after state, none of our insurers have left the state and no businesses have thrown in the towel because of this benefit. Indeed, the impact on premiums has been negligible. In Indiana, the DOI called the financial impact “unmeasurable” even years after the coverage became effective.

The insurance industry’s own association – the Council for Affordable Health Insurance – estimates that mandated autism benefits increase premium costs by LESS than 1%. (See chart)

We’ve have an independent cost analysis prepared specifically for Michigan. I understand that the analyst will be here to testify next week, but I can tell you that he also arrived at less than 1%. (See attachment.)

Some opponents say this bill will increase premiums 2-3% and tell you that 5500 people will lose insurance for every 1% that premiums increase. Before you accept that, I ask you to hold our opponent’s feet to the fire on this prediction of a devastating premium increase. Have they shown you the math they used to come up with a 2-3% prediction? You’ve got a document that shows our independent analyst’s math and arrives at approximately \$xxx/month. Better yet, the insurance industry could show you their actual claims data. Insurance companies in Indiana and Minnesota have been tracking this data for years, and they know exactly how much it costs to fully cover autism.

Further, in states where this law has passed, the overall impact on the economy has been positive, particularly in terms of job creation. Thousands of people have been trained and are now working full-time as therapists with children with autism.

Question #1 Don't the schools provide this therapy? Or shouldn't the schools provide it?

Autism is a medical condition that is diagnosed by a medical doctor, not by a school principal. It is not a learning disability.

Federal law – the Individuals with Disabilities Education Act (IDEA) – does not charge the schools with ameliorating a child's medical condition; it charges the schools with providing the child a meaningful education.

Under IDEA, schools must accommodate disabilities in the course of educating children, but schools do not, cannot, and should not be tasked with treating the disabling condition.

For example, schools accommodate a child with diabetes by allowing the child to receive insulin injections at school, so that the child can function and thus learn. But, just as society does not rely on schools to pay for the insulin, nor should we put the burden on schools to pay for the treatment a child with autism needs in order to function in a school setting.

Further, to be effective, ABA therapy must be administered on a one-on-one basis. Do the Michigan schools have such plentiful resources that they can employ a trained one-on-one therapist for each child with autism and hire a Board Certified Behavior Analyst to supervise in each school or at least each district?

And finally on the “educational” issue, even to the extent that some schools attempt to employ ABA principles in educating children with autism, this does not magically render ABA “educational and thus exempt from insurance coverage,” just as the schools’ provision of speech therapy does not render speech therapy exempt from insurance coverage. Schools that use ABA work only on educational goals for a child; they do not work on other skills that children with autism acquire through intensive ABA therapy, such as potty-training, dressing, use of utensils, toothbrushing, bathing, and other daily living skills that typical children acquire naturally through imitation.

Calling ABA “educational” and thus not subject to insurance coverage is just another ploy to get out of paying for it. First it wasn't covered because it was experimental; now it's not covered because it's educational. And yet, TriCare, the Department of Defense health insurance plan for military, has been covering Applied Behavior Analysis for years.

Question #2 Well, how about Medicaid?

Some states have attempted to handle this issue by creating autism-specific Medicaid waivers that cover ABA. Two problems with this approach, one practical and one philosophical.

1- Not enough funding. State must fund, and even with federal match, no state has been able to pour enough money into a waiver program to serve all of the kids with autism. Very long waiting lists, during which opportunity for maximum “recovery” disappears.

2- Socialized medicine

Question #3: Don't some insurers already cover autism?

Even to the extent that insurance policies currently cover autism, they do not cover the treatment that is most effective and most commonly-prescribed for autism. Perhaps there is no blanket exclusion in the policy for autism, but there are exclusions for behavioral therapy, for habilitative treatment, or any number of other things that make the treatment unavailable. Some insurers have specific written policy statements stating that ABA will not be covered. (See Cigna & BCBS coverage positions).

Cancer/chemo analogy.

I don't believe in telling insurance companies what they must cover.

Private contract between private parties.

I felt same way 5 years ago. But I've learned a lot in those 5 years. I've learned that the theories I studied in law school about market failure due to unequal bargaining power are true and real. This is a classic case of market failure. The industry has proven that it is not going to step up to the plate and do the right thing, thereby forcing your hand. And you know, granted they are contracts between private parties, but we as a society have already determined that we believe in some degree of interference in these particular contracts. If we didn't, we wouldn't need a DOI. The state regulates insurance affairs, and, because the insurance industry refuses to update its coverage positions to align with current science, the state should step in here.

Why should we single out this one disease for coverage?

What other disease do you know of that insurance purports to cover but doesn't cover the single most effective, accepted, and commonly prescribed treatment for? Name another disease for which we know of a treatment that undeniably works and that is evidence-based, but insurance won't cover that particular treatment.

Some insurers claim that the autism community is seeking special treatment by asking to have a particular treatment covered. They say we're seeking special treatment because ABA is not covered for any other diagnoses. Actually, we are seeking equal treatment. All we are asking is that insurance cover the standard treatment protocol for this condition. Would we tell breast cancer patients they were seeking special treatment if they asked to have mastectomies covered? Would the insurance industry refuse to cover that particular treatment because they don't cover it for any other disease? Of course not. Equal treatment means covering for each disease the standard treatment protocol for that disease.

This law would not be very effective because only a small percentage of Michigan residents would be subject to its terms

The fact that many Michigan residents are governed by ERISA plans or other plans that are subject to federal, not state, regulation is not a reason to not help the residents you can reach. If you saw a sinking boat with 10 people on board on the verge of drowning, and you had 3 life jackets, would you toss the 3 life jackets, or would you hold onto them because you didn't have 10?

Effect on ERISA plans; many self-insured employers follow suit.

Further, if some coverage exists within the state, parents of autistic children can change jobs to find coverage. If none exists, they cannot.

Why aren't other therapies, such as Floortime, included?

This bill is written in such a way as to encompass evidence-based treatment. It is not meant to favor one brand over another, but at present, Applied Behavior Analysis (ABA) is the only treatment of its kind that is empirically validated. We do not question the judgment of parents who use or try other types of treatments; I've tried others with my own son. But we didn't think it was fair to ask insurance to cover treatments which are not yet validated with peer-reviewed research.

As to Floortime specifically (also known as DIR), we simply defer to the report of the American Academy of Pediatrics, which states:

*"Published evidence of the efficacy of the DIR model is limited to an unblinded review of case records (with significant methodologic flaws, including inadequate documentation of the intervention, comparison to a suboptimal control group, and lack of documentation of treatment*

*integrity and how outcomes were assessed by informal procedures) and a descriptive follow-up study of a small subset (8%) of the original group of patients."*

Because there's no license for behavior analysts, we'd be forced to cover just anyone.

There is a well-established, national certification for behavior analysts that has already been accepted by states, by the military insurance (TRICARE), and by insurers who operate in states where this law has been passed. In those states, insurers have been able to limit payments only to board-certified providers (or equivalent), and the lower-level therapists who lack certification are paid through the board-certified provider. The requirements for board certification are extremely stringent and there are continuing education requirements. Many insurers have already examined these requirements and satisfied themselves that it is an appropriate credential for payment. (Show BCBS implementation documents from South Carolina).

Does this bill take away the insurers' ability to use cost-control mechanisms? No. The bill neither indicates that insurers may not use their normal cost-control measures nor is it the intent of the autism community to remove their ability to do so. We are not asking for special treatment here; we are asking for equal treatment. We are asking to be treated equally in that insurance should cover the standard, well-accepted treatment for autism, just as it covers standard, accepted treatments for other diseases. But we're not asking to get out of deductibles, copayments, or even other typical cost-control mechanisms like coordination of benefits, restrictions on family members providing service, or reviews for medical necessity. (See treatment review clause).

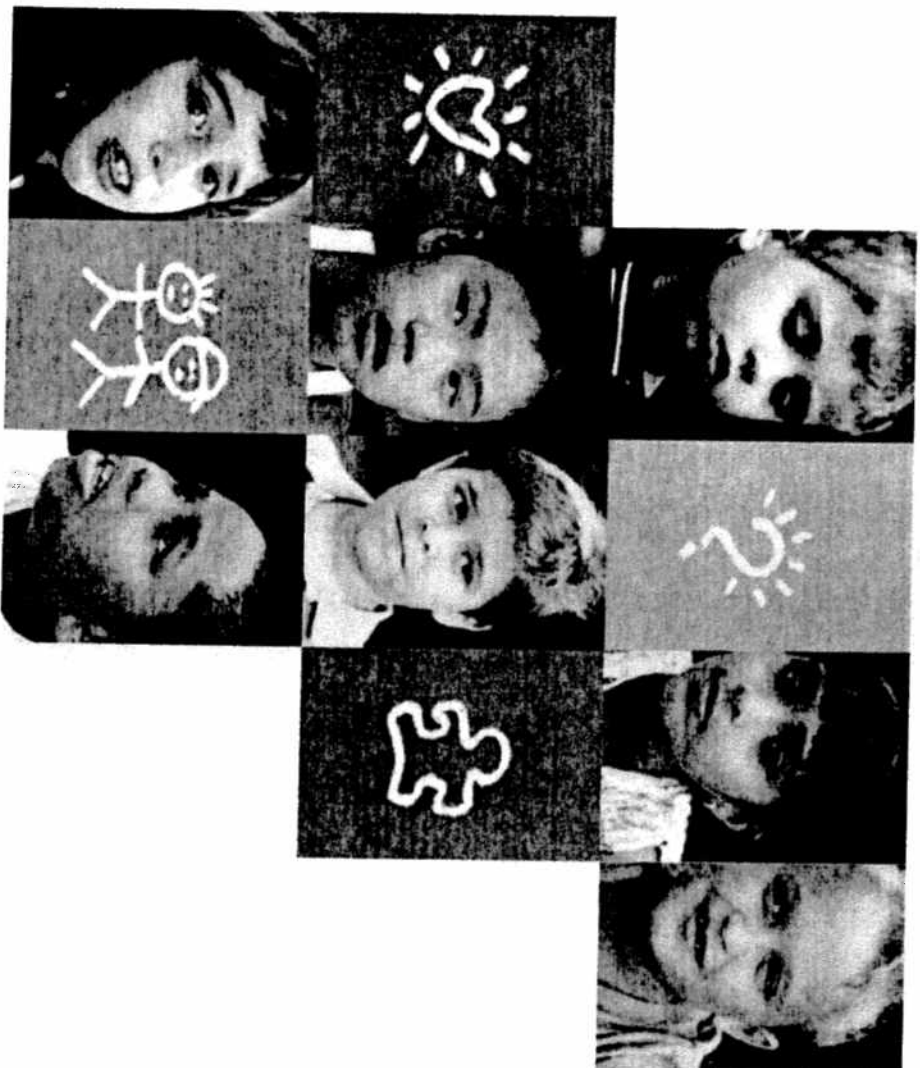
#### SUM UP

I was a law professor for 7 years, and I spent much of that time thinking about this issue and how best to resolve it. [Medicaid? Education? May all have role to play and they're trying. But it is insurance industry that is most not doing its part. Getting off the hook scot-free and not paying its fair share of the burden]. After years of examining the issue, I've yet to come up with a better solution than what is being proposed here.

Finally, I would ask you to pass this bill because it is simply the right thing to do. I hear so many people complain about paying taxes and griping about how high taxes are. It is my dream for my son that someday he may get to pay taxes. And I bet many parents in this room share that dream.

Thank you for taking the first step toward giving Michigan children the treatment that kids in other states are now getting by voting this bill out of committee.



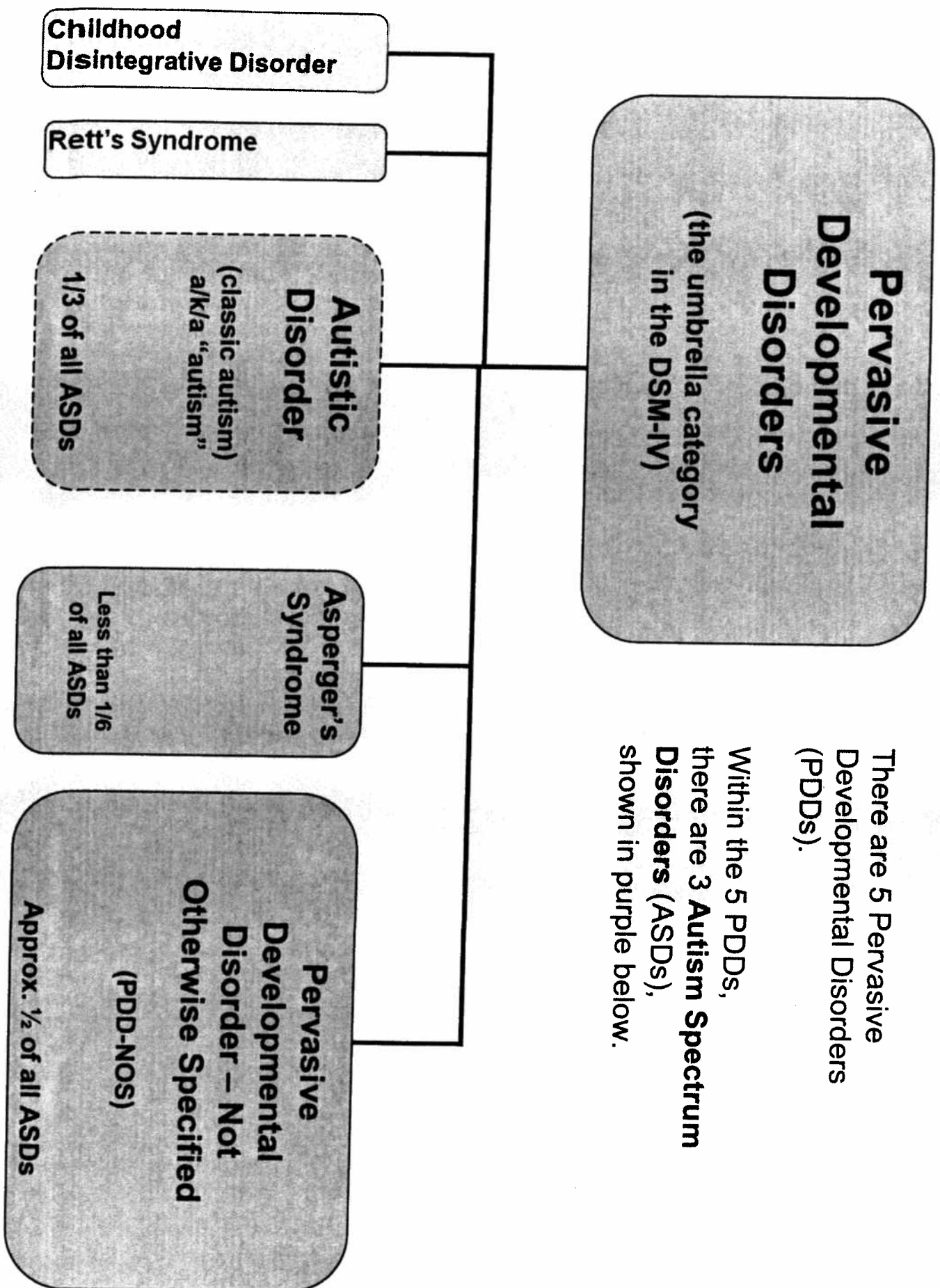


# Autism Insurance in Michigan

Lorri Unumb, Esq.  
Autism Speaks







There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below.



# Applied Behavior Analysis: A Sample Program

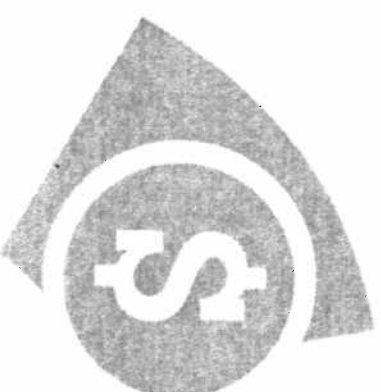
- Consultant
  - Highly educated and trained
  - Board certified
  - Evaluates, designs, trains
  - 3-6 hours per month
- Mid-level supervisor (lead therapist)
  - Highly educated and trained
  - May be board certified
  - Updates programming; trains; oversees
  - 6 hours per week
- Line therapists
  - May be college students, trained by above
  - Provide 40 hours per week of direct therapy, usually in 3-hour shifts





# Applied Behavior Analysis: Cost of a Sample Program

- Consultant
  - 3-6 hours per month
  - \$100-\$150/hour
  - 6 hours x \$150 = \$900/month
  - \$900 x 12 months = **\$10,800**
- Mid-level supervisor (lead therapist)
  - 6 hours per week
  - \$30-\$60/hour
  - 6 hours x \$60 = \$360/week
  - \$360/week x 52 weeks = **\$18,720**
- Line therapists
  - 40 hours per week
  - \$10 - \$20/hour
  - 40 hours x \$20 = \$800/week
  - \$800/week x 52 weeks = **\$41,600**
- $\$10,800 + \$18,720 + \$41,600 = \$71,120$





# Comparison of State Autism Benefits

	S.C.	Minnesota BCBS	Ariz.	Montana	Indiana	Penn.
Annual Cap	\$50K (only on ABA)	Unlimited	\$50K thru 8; \$25K 9-16	\$50K thru 9; \$20K 9-18	Unlimited	\$36K
Diag- nosed by age	8	n/a	n/a	n/a	n/a	n/a
Benefits until age	16	No age cap	17	18	No age cap	21

Treatment must be prescribed by licensed physician or psychologist.





# **Excerpt from 2008 Report of Council of Affordable Health Insurance: “Health Insurance Mandates in the States”**

<b>BENEFITS:</b>	<b>Est. Cost</b>	<b>#</b>
Alcoholism	1-3%	45
Autism	<1%	11
Contraceptives	1-3%	31
In Vitro Fert.	3-5%	13
Prescriptions	5-10%	2

Available at [www.CAHI.org](http://www.CAHI.org).

The Council for Affordable Health Insurance is a research and advocacy association of insurance carriers active in the small group, individual, HSA, and senior markets. CAHI is an active advocate for market-oriented solutions to the problems in America's health



# Self-Funded ERISA Plans

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Symantec
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- IBM
- Mayo Clinic
- Raytheon
- Symantec
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Michelin
- Greenville Hospital System





“[N]o  
disability  
claims more  
parental  
time and  
energy than  
autism.”

New York Times,  
12/20/04



# The Lifetime Distribution of the Incremental Societal Costs of Autism

Michael L. Ganz, MS, PhD

**Objective:** To describe the age-specific and lifetime incremental societal costs of autism in the United States.

**Design:** Estimates of use and costs of direct medical and nonmedical care were obtained from a literature review and database analysis. A human capital approach was used to estimate lost productivity. These costs were projected across the life span, and discounted incremental age-specific costs were computed.

**Setting:** United States.

**Participants:** Hypothetical incident autism cohort born in 2000 and diagnosed in 2003.

**Main Outcome Measures:** Discounted per capita incremental societal costs.

**Results:** The lifetime per capita incremental societal cost of autism is \$3.2 million. Lost productivity and

adult care are the largest components of costs. The distribution of costs over the life span varies by cost category.

**Conclusions:** Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general. These results may imply that physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

*Arch Pediatr Adolesc Med.* 2007;161:343-349

**A**UTISM IS A VERY EXPENSIVE disorder costing our society upwards of \$35 billion in direct (both medical and nonmedical) and indirect costs to care for all individuals diagnosed each year over their lifetimes.<sup>1</sup> Given the financial and nonfinancial costs we face and given increasingly more options for treatment and possibly for prevention, information on the distribution of costs is needed to help us decide on how to best allocate scarce resources to support individuals with autism and their families. Because the complementary (or competing) treatment and prevention strategies currently available, or yet to be developed, vary in effectiveness or implementation costs, understanding how total costs due to autism are distributed across the life cycle is important to make better decisions.

Relatively little is known about the societal costs of autism, in total and at different points across the life cycle. In earlier work, the per capita and total societal costs for individuals with autism were described.<sup>1</sup> Although the per capita and societal costs were described overall and across 17 components of direct medical, direct nonmedical, and indirect costs, age-specific costs were not. Because certain cat-

egories are more relevant and more costly and because these costs are borne by different parties at different ages, presenting the age distribution of the costs of autism can provide policy makers information that is helpful for cost-utility analyses and for current and future resource planning activities. The focus of this study is to present estimates of the costs of autism along with some detail on how the estimates were constructed. Although no clinical data are presented, these data should be useful to health care professionals, families, and agencies in planning for future care, especially with respect to nonmedical costs.

## METHODS

A detailed description of the sources of data and computational methods used to compile the costs of autism has been presented elsewhere.<sup>1</sup> Briefly, cross-sectional cost data from different age groups were used to create prevalence-based cost estimates that approximate incidence-based estimates (ie, those constructed by longitudinally tracking an incident cohort over time). A prevalence-based cohort, also known as a synthetic, or hypothetical, cohort,<sup>2</sup> allows us to approximate the lifetime experiences of a single incident cohort by using the prevalence-based cost patterns as if

**Author Affiliations:** Abt Associates Inc, Lexington, and Harvard School of Public Health, Boston, Mass.

they were observed longitudinally from an incident cohort. Although an incidence-based cost-of-illness approach is more appropriate because it captures the full experience of autism, including any comorbid conditions, formidable data requirements preclude it.<sup>3</sup>

The total costs of autism equal the sum of its direct and indirect costs. Direct costs measure the value of goods and services used and indirect costs measure the value of lost productivity due to autism. These direct and indirect costs represent the value of other activities that these resources could have purchased (ie, opportunity costs).<sup>4,5</sup> Physician and other professional services, hospital and emergency department services, drugs, equipment and other supplies, and medically related travel and time costs are typical components of direct medical costs. Direct medical costs were obtained either from the literature or from an analysis of the Medical Expenditure Panel Survey (MEPS)<sup>6</sup> and the National Health Interview Survey (NHIS).<sup>7</sup> Special education, transportation, child care and babysitting, respite care, out-of-home placement, home and vehicle modifications, and supported employment services are typical components of direct nonmedical costs. Nonmedical costs were obtained from the literature. Multiple cost estimates within categories were averaged to obtain a single cost estimate for each category. Indirect costs are the value of lost or impaired work time (income), benefits, and household services of individuals with autism and their caregivers because of missed time at work, reduced work hours, switching to a lower-paying but more flexible job, or leaving the workforce. Indirect costs were computed using a human capital approach<sup>3,8</sup> that combines average earnings, benefits, and household services with information on average work-life expectancies and labor force participation rates for men and women at different ages.

In the analyses that follow, the incremental costs of autism are presented, which are defined as those additional costs that are due exclusively to autism. For example, costs due to use of medical services for periodic well-child preventive care or care related to the common cold are not considered herein because those costs are common to children with and without autism; however, costs specifically due to autism are considered herein. When incremental costs were not available or otherwise specifically presented in the source materials, they were computed by subtracting national average costs calculated from the MEPS from the costs reported in the source documents. For example, if a source document presented an average cost of \$X for all children with autism and the national average for all children for that same category was \$Y, then the incremental cost was computed as \$(Y-X). Because of the broad impact of autism on families, insurers, taxpayers, and society and because of the considerable public autism funding, a societal perspective was used, as recommended by the Panel on Cost-effectiveness in Health and Medicine.<sup>8</sup>

The Harvard School of Public Health Human Subjects Committee had previously exempted this study from institutional approval.

## DIRECT COSTS

### Literature Review

An in-depth targeted literature review concentrating on US-based studies was conducted to obtain data on use and costs. British and Canadian studies were also used when data were otherwise unavailable. Data on physician, outpatient, clinic services, dental care,<sup>9</sup> prescription medications,<sup>9-11</sup> complementary and alternative therapies,<sup>12-18</sup> behavioral therapies,<sup>19-22</sup> hospital and emergency services,<sup>9,23</sup> allied health, equipment and supplies, home health,<sup>9</sup> and medically related travel<sup>9</sup> were classified as direct medical. Data on child care,<sup>9,19</sup> adult care,<sup>19,20</sup> respite and family care,<sup>9,19,20</sup>

home and care modifications,<sup>9,24</sup> special education,<sup>19,20,23-27</sup> supported employment,<sup>20,28-34</sup> and other costs<sup>9,24</sup> were classified as direct nonmedical. Although some dimensions of care may be misclassified between direct medical and direct nonmedical (for example, many special education programs provide behavioral therapies), because the degree of misclassification is not known, no corrections were made. Costs, as reported in the source materials, were inflated to 2003 US dollars using the all-item consumer price index.<sup>35</sup> State-specific costs were transformed to national averages<sup>36</sup> and foreign costs were converted to US costs using the latest available Federal Reserve exchange rates.<sup>37</sup> Use measures were translated to costs by multiplying the use measures by age group-specific survey-adjusted average costs from the MEPS.<sup>6</sup> More in-depth information on how the cost estimates were constructed from these sources is available elsewhere<sup>1</sup> and in a technical appendix available on request.

## Survey Analysis

Data from the NHIS<sup>7</sup> and the MEPS<sup>6</sup> were also used to supplement data on costs of autism and to also compute average costs for use in deriving the incremental costs of autism. Because confidentiality concerns constrain the MEPS to only report the first 3 digits of diagnosis codes, individuals with an *International Classification of Diseases, Ninth Revision (ICD-9)* diagnosis code of 299, which includes autism diagnoses (299.0x) as well as disintegrative psychoses (299.1x) and early childhood psychoses (299.8x/299.9x), were used as proxies for individuals with autism. Specific autism questions were available in the NHIS during 1997-2000. Information from those questions was combined with an ICD-9 diagnosis code of 299 in the NHIS and was linked to the MEPS to increase the number of usable cases. Survey-adjusted means for expenditures were then computed as described earlier. Further information is available elsewhere<sup>1</sup> and from the technical appendix.

## INDIRECT COSTS

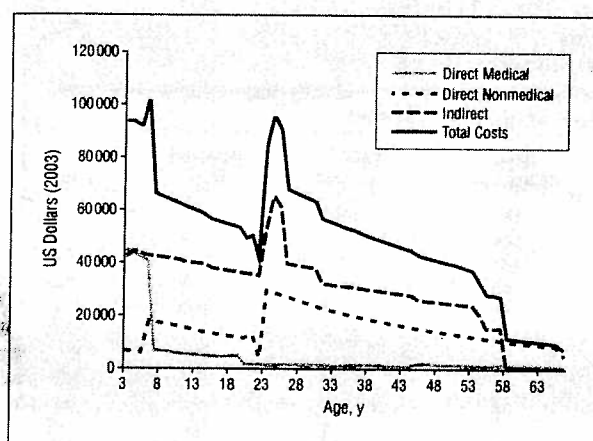
Productivity losses for people with autism were estimated by combining standard average work-life expectancies for all men and women taken from the economics literature (ages 23-57 years for men and 23-53 years for women),<sup>34</sup> with average income and benefits (from Tables 696 and 628 of the *Statistical Abstract of the United States*<sup>36</sup>) and estimates of age- and sex-specific labor force participation rates.<sup>38</sup> Average incomes are projected for future years based on estimated productivity growth rates<sup>35</sup> to estimate average total earnings and benefits at each age. These estimates are adjusted for the fact that while some adults with autism are unable to work, others are (35% of adults with lower levels of disability and 10% of adults with higher levels of disability work in supported work environments). Finally, the lost value of sex-specific household services is added.<sup>3,39</sup> These estimates do not account for the effects of taxes or lost leisure time. Similar methods were used to estimate productivity for parents. Fathers of children with lower levels of disability were assumed to be unemployed 10% of the time (and working full-time during the remaining 90%) and mothers were assumed to be unemployed 55% of the time (and were working half-time 25% of the time and full-time, 20%).<sup>40,41</sup> Fathers of children with higher levels of disability were assumed to be unemployed 20% of the time and mothers were assumed to be unemployed 60% of the time (and were working half-time 30% of the time and full-time, 10%). These assumptions were combined with the same average earnings, benefits, productivity growth, labor force participation rates as used for individuals with autism, and the appropriate work-life expectancies. These estimates assumed households in which both a mother and a father care for 1 child with autism. These estimates will differ based on different family configurations.



**Table 1. Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism\***

Age Group, y	Average Per Capita Cost per Age Group			Total Per Capita Cost
	Direct Medical	Direct Nonmedical	Indirect	
3-7	35 370	10 805	43 066	446 203
8-12	6013	15 708	41 138	314 297
13-17	5014	13 550	38 453	285 082
18-22	2879	10 720	36 090	248 446
23-27	1574	27 539	51 740	404 260
28-32	1454	23 755	35 757	304 828
33-37	1389	20 492	30 852	263 662
38-42	1283	17 676	29 132	240 457
43-47	1440	15 248	26 600	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 776	151 790
58-62	1218	9489	0	53 535
63-66	1027	7908	0	35 738
Total lifetime costs	305 956	978 761	1 875 667	3 160 384

\*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.



**Figure 1.** Age distribution of incremental societal costs of autism (present value).

## CALCULATING COSTS

To the extent possible, cost estimates were derived for higher- and lower-functioning individuals as they were presented in the literature. Semidependent, independent, or those individuals described as having high-functioning autism were classified in the higher-functioning category. Dependent individuals or those not described as having high-functioning autism were classified in the lower-functioning category. Based on data presented in Fombonne,<sup>12</sup> the prevalence of higher-functioning autism is assumed to be 54%. The male-female ratio is assumed to be 4:1. Weighted average per capita costs were computed based on the assumed distribution of lower- and higher-functioning status and the male-female ratio. Age 3 years was considered to be the baseline age (age at diagnosis) and 2003 was the baseline year. Because there is some evidence that people with autism have reduced life expectancies,<sup>41-46</sup> costs were tabulated through age 66 years for males and through age 65 years for females. Costs were discounted to present value (to age 3 years) using a discount rate of 3% as recommended by the Panel on Cost-effectiveness in Health and Medicine.<sup>8</sup> Costs in future years were discounted, or deflated, to reflect the time value of money: a dollar today is worth more

than a dollar in the future. In doing so, all costs were adjusted for the different periods in which they were incurred. In other words, dollars at different ages become comparable. Because health care resource investments, such as in the case of autism research and treatment budgets, incur costs in the present and potentially realize the benefits in the future, it is common to discount future flows of costs (and benefits) to present value. Although 3% is the currently used standard for a discount rate, this rate is varied in the sensitivity analyses described in the next subsection.

## SENSITIVITY ANALYSES

In previous work, the robustness of the overall cost estimates was assessed using 1-way sensitivity analyses and conclusions were mostly robust to changes in many key parameters.<sup>1</sup> However, the total costs were found to be most sensitive to changes in the discount rate and to changes in the assumed level of indirect costs. Because variations in indirect costs will not substantially change the pattern of costs over the life cycle, herein focus is placed on the discount rate.<sup>8</sup> The discount rate is varied between 2% and 5% as suggested by Gold et al.<sup>8</sup>

## DEFINITION OF AUTISM

Many of the sources of data simply used the term *autism* and did not differentiate between the different autism spectrum disorders. Reflecting the literature, the term *autism* herein is used in an inclusive manner to mean all disorders in the spectrum. Given the nature of many of the nonmedical and indirect costs, it is likely that those costs are more representative of more disabled individuals. Older sources<sup>9</sup> may have only included lower-functioning children and individuals in their definitions of autism. However, varying the proportions of lower- and higher-functioning individuals does not substantially change conclusions about overall lifetime costs.<sup>1</sup>

## RESULTS

In the Tables that follow, the average per capita costs by category are presented in 5-year intervals (the full Tables

**Table 2. Age-Specific and Lifetime per Capita Incremental Societal Direct Costs of Autism\***

Age Group, y	Average per Capita Cost per Age Group						Travel
	Physician and Dental	Drugs	CAM Therapies	Behavioral Therapies	Emergency and Hospital	Home Health	
3-7	1147	147	198	32 501	828	467	81
8-12	577	153	109	4033	768	303	70
13-17	435	131	50	3479	591	267	60
18-22	426	129	33	1254	852	132	52
23-27	496	124	28	0	774	106	45
28-32	507	114	25	0	682	87	39
33-37	547	98	21	0	598	93	33
38-42	540	84	18	0	522	90	29
43-47	765	72	16	0	426	137	25
48-52	845	61	14	0	352	154	21
53-57	851	52	12	0	292	65	18
58-62	810	44	10	0	323	14	16
63-66	632	34	9	0	301	39	14
Total lifetime costs	42 259	6180	2704	206 337	36 235	9738	2503

Abbreviation: CAM, complementary and alternative medicine.

\*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

**Table 3. Age-Specific and Lifetime per Capita Incremental Societal Direct Nonmedical Costs of Autism\***

Age Group, y	Average per Capita Cost per Age Group						Other
	Child Care	Adult Care	Respite Care	Home Improvements	Special Education	Supported Work	
3-7	4636	0	1100	161	4585	0	323
8-12	3999	0	948	139	10 343	0	278
13-17	3450	0	818	120	8922	0	240
18-22	2907	0	706	10	6247	0	851
23-27	0	25 064	0	9	0	836	1630
28-32	0	21 620	0	8	0	721	1406
33-37	0	18 650	0	7	0	622	1213
38-42	0	16 087	0	6	0	537	1046
43-47	0	13 877	0	5	0	463	903
48-52	0	11 970	0	4	0	399	778
53-57	0	10 326	0	4	0	291	672
58-62	0	8907	0	3	0	0	579
63-66	0	7423	0	3	0	0	483
Total lifetime costs	74 963	662 192	17 858	2388	150 483	19 349	51 528

\*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

are available as eTables 1-4 at <http://archpediatrics.com>). **Table 1** and **Figure 1** display the incremental societal direct medical, direct nonmedical, and indirect costs. Direct medical costs are quite high for the first 5 years of life (average of around \$35 000), start to decline substantially by age 8 years (around \$6000), and continue to decline through the end of life to around \$1000. Direct nonmedical costs vary around \$10 000 to approximately \$16 000 during the first 20 years of life, peak in the 23- to 27-year age range (around \$27 500), and then steadily decline to the end of life to around \$8000 in the last age group. Indirect costs also display a similar pattern, decreasing from around \$43 000 in early life, peaking at ages 23 to 27 years (around \$52 000), and declining through the end of life to \$0.

**Table 2** displays the individual components of the incremental societal direct medical costs. Considered over the entire life span, direct medical costs make up 9.7% of total discounted lifetime costs. Behavioral therapies, which are the largest component of direct medical costs, make up 6.5% of total discounted lifetime costs.<sup>1</sup> However, behavioral therapies, as presented herein, are only relevant for children 19 years or younger. The large direct medical costs early in life are driven primarily by behavioral therapies that cost around \$32 000 during the first 5-year age group and decline from about \$4000 in the 8- to 12-year age group to around \$1250 for the 18- to 22-year age group. Physician and dental costs are initially high, then decrease, but increase again in later life. Prescription drugs, complementary and alternative therapies, and hospital and emergency services are also relatively

**Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism\***

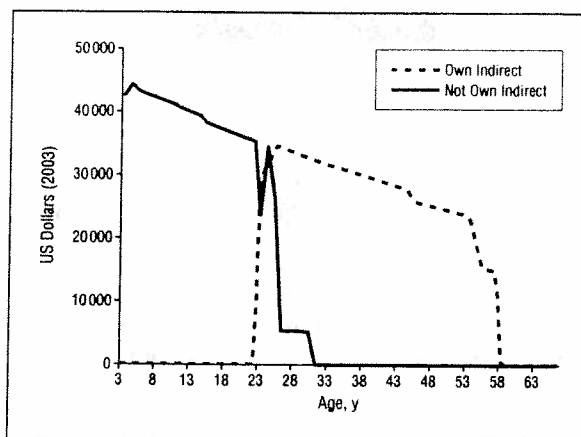
Age Group, y	Average per Capita Cost per Age Group	
	Own Indirect	Not Own Indirect
3-7	0	43 066
8-12	0	41 138
13-17	0	38 453
18-22	0	36 090
23-27	32 703	19 036
28-32	32 620	3136
33-37	30 852	0
38-42	29 132	0
43-47	26 600	0
48-52	24 531	0
53-57	17 776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	904 595

\*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

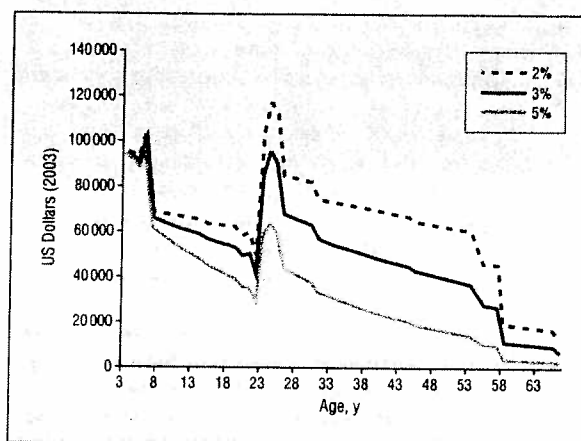
high initially but steadily decline. Some costs decline less smoothly than others because of different availability of cost-by-age estimates in the literature.

**Table 3** displays the individual components of the incremental societal direct nonmedical costs. Nonmedical costs, except during ages 3 to 7 years, are more expensive than direct medical costs and make up 31% of total discounted lifetime costs.<sup>1</sup> Different costs become relevant at different ages, which contributes to the dips and spikes in the direct nonmedical line in Figure 1. Child care and respite costs, which average about \$5700 in early ages to around \$3600 at ages 18 to 22 years, contribute far less (3% of total discounted lifetime costs) than adult care costs (21% of total discounted lifetime costs), which range from around \$25 000 at ages 23 to 27 years to around \$7400 at ages 63 to 66 years. Special education costs, which make up 4.8% of total discounted lifetime costs, range from around \$12 000 at age 6 years (costs for ages 3-5 years are assumed to be zero) to around \$6200 at ages 18 to 22 years, and supported employment costs range from around \$800 at ages 23 to 37 years to around \$300 at ages 53 to 57 years (age 57 years is the assumed end of working life).

**Table 4** displays the components of the incremental societal indirect costs. Indirect costs are by far the largest component of the total incremental societal costs of autism (59.3% of total discounted lifetime costs).<sup>1</sup> Own indirect costs, which make up 30.7% of total discounted lifetime costs, range from around \$33 000 at ages 23 to 27 years to around \$18 000 at ages 53 to 57 years. Not own (assumed herein to be parents') indirect costs, which make up 28.6% of total discounted lifetime costs, range from around \$43 000 at ages 3 to 7 years, when parents are assumed to be about 33 to 37 years of age, to around \$19 000 at ages 23 to 27 years, when parents are assumed to be 53 to 57 years of age, to around \$3000 per year for the next 5 years until the end of the average work life. Although total indirect costs spike at ages 23



**Figure 2.** Age distribution of own and not own indirect incremental costs (present value).



**Figure 3.** Age distribution of total incremental societal costs of autism computed at different discount rates.

to 27 years, because of the overlapping own and not own indirect costs, as **Figure 2** indicates, at any given time from age 3 years through age 57 years, there is a substantial and smoothly declining level of indirect costs. Figure 2 also dramatically illustrates, at least for this model, the transition from exclusive parental lost productivity almost immediately to lost own productivity.

## SENSITIVITY ANALYSES

Sensitivity analyses using 2% and 5%, which are common upper and lower bounds, reveal that the patterns of age-specific expenditures are similarly shaped. **Figure 3** displays total costs using 2%, 3%, and 5% as the discount rates. There is an inverse relationship between the discount rate and the weight placed on future costs: lower discount rates place greater weight on future costs and higher rates place less weight on future costs. As a result, total present value costs will be larger the smaller the discount rate. The maximum difference in total costs between the 5% scenario and the 2% scenario (about \$53 000) occurs at age 24 years and the average difference in costs between the 5% and 2% scenarios is about \$31 000.

This article presents the first description, to my knowledge, of the societal costs of autism in the United States across all ages of the life span and contributes not only to the literature on the costs of autism but also to the literature on age-specific health care costs in general. As was previously reported, the total annual societal per capita cost of caring for and treating a person with autism in the United States was estimated to be \$3.2 million and about \$35 billion for an entire birth cohort of people with autism.<sup>1</sup> Sensitivity analyses revealed that these lifetime costs could range from \$13 billion to \$76 billion depending on the underlying assumptions of the model. Although those estimates are highly conservative because they exclude a number of important elements (such as legal costs that families incur to secure services<sup>47,48</sup>; lost productivity of those other than parents; the costs of genetic testing; the full costs of alternative therapies, including diets; the costs of adverse outcomes of potentially dangerous treatment modalities; and costs associated with immunization-avoidance behaviors<sup>48</sup>), they are valuable because they add information to a relatively underdeveloped literature. As treatment and, perhaps prevention, strategies are developed, knowledge of when costs are incurred relative to when benefits are expected is important for clinical decision-making and cost-effectiveness analysis efforts.

Knowledge about age-specific per capita incremental societal costs is particularly important because, as opposed to the summary lifetime data presented previously,<sup>1,25,47</sup> age-specific data illuminate the relative magnitudes of different types of costs at different ages. Given that at different ages different segments of society are responsible for absorbing these costs, this detailed disaggregation of costs can provide even more valuable information to planners, policy makers, and even to families making decisions that can affect current and future financial health, especially as they consider the fact that at various points in the life cycle different costs are more germane than others.

Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. Adult care, which has the largest lifetime cost of all direct costs, is typically more than 5 times larger than the next 3 largest costs, which include care incurred during childhood (behavioral therapies, child/respite care, and special education). Alemayehu and Warner<sup>49</sup> reported that the typical American spends about \$317 000 over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65 years. In contrast, people with autism incur about \$306 000 in incremental direct medical costs, implying that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years.

These results, especially on the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs, have important implications for those aging mem-

bers of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general. Perhaps physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

Although this study is limited by a number of factors, it is the first of its kind, to my knowledge, and can shed insight into the lifetime distribution of autism costs and also motivate future, more rigorous studies. The cost model presented herein is based on a number of simplifying assumptions and relies on sometimes incomplete and old information. These caveats should be kept in mind when using these estimates for policy or practice decision making. The results presented herein for direct medical costs are consistent with recently published data on health care use and costs for children with autism. Gurney et al<sup>50</sup> reported that, relative to children without autism, children with autism, as reported by their parents, experience a significantly higher number of preventive visits and emergency and nonemergency hospital visits. Croen et al<sup>51</sup> reported, based on administrative data from the Northern California Kaiser Permanente Medical Care program, that children with autism incurred 2.5 times as much outpatient costs, 2.9 times as much inpatient costs, and 7.6 times as much medication costs as randomly selected children without autism. Pursuing a research agenda of both carefully and systematically documenting the costs of autism in the United States can be helpful in improving these estimates. Prospectively tracking the life experiences of individuals with autism and their families and obtaining a wide variety of data on the different sources of services for people with autism can provide this more complete picture. Prospectively collected clinical and quality-of-life data combined with cost data will be even more useful for understanding the societal costs, both financial and nonfinancial, of caring for those members of our society with autism at every age of the life course.

Accepted for Publication: November 16, 2006.

Correspondence: Michael L. Ganz, MS, PhD, Abt Associates Inc, 181 Spring St, Lexington, MA 02421 (mganz@hsph.harvard.edu).

Financial Disclosure: None reported.

Additional Information: eTables 1-4 are available at <http://archpediatrics.com>.

## REFERENCES

1. Ganz ML. The costs of autism. In: Moldin SO, Rubenstein JLR, eds. *Understanding Autism: From Basic Neuroscience to Treatment*. Boca Raton, Fla: Taylor and Francis Group; 2006.
2. National Center for Health Statistics. NCHS definitions: synthetic cohort. December 16, 2004. <http://www.cdc.gov/nchs/data/nchsdefs/syntheticcohort.htm>. Accessed January 5, 2005.



3. Waitzman NJ, Scheffler RM, Romano PS. *The Costs of Birth Defects: Estimates of the Value of Prevention*. Lanham, Md: University Press of America, Inc; 1996.
4. Pindyck RS, Rubinfeld DL. *Microeconomics*. 5th ed. Upper Saddle River, NJ: Prentice Hall; 2000.
5. Rice DP, Hodgson TA, Kopstein AN. The economic costs of illness: a replication and update. *Health Care Financ Rev*. 1985;7:61-80.
6. Agency for Healthcare Research and Quality. The Medical Expenditure Panel Survey. <http://www.ahrq.gov/data/mepsix.htm>. Accessed January 3, 2005.
7. Centers for Disease Control and Prevention. The National Health Interview Survey. December 16, 2004. <http://www.cdc.gov/nchs/nhis.htm>. Accessed January 3, 2005.
8. Gold MR, Siegel JE, Russell LB, Weinstein MC, eds. *Cost-Effectiveness in Health and Medicine*. New York, NY: Oxford University Press; 1996.
9. Birenbaum A, Guyot D, Cohen HJ. *Health Care Financing for Severe Developmental Disabilities*. Washington, DC: American Association on Mental Retardation; 1990.
10. Aman MG, Van Bourgondien ME, Wolford PL, Sarpahre G. Psychotropic and anticonvulsant drugs in subjects with autism: prevalence and patterns of use. *J Am Acad Child Adolesc Psychiatry*. 1995;34:1672-1681.
11. Martin A, Scabill L, Klin A, Volkmar FR. Higher-functioning pervasive developmental disorders: rates and patterns of psychotropic drug use. *J Am Acad Child Adolesc Psychiatry*. 1999;38:923-931.
12. Aman MG, Lam KS, Collier-Crespin A. Prevalence and patterns of use of psychoactive medicines among individuals with autism in the Autism Society of Ohio. *J Autism Dev Disord*. 2003;33:527-534.
13. Eisenberg DM, Kessler RC, Foster C, Norlock FE, Calkins DR, Delbanco TL. Unconventional medicine in the United States: prevalence, costs, and patterns of use. *N Engl J Med*. 1993;328:246-252.
14. Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafos J. Internet survey of treatments used by parents of children with autism. *Res Dev Disabil*. 2006;27:70-84.
15. Langworthy-Lam KS, Aman MG, Van Bourgondien ME. Prevalence and patterns of use of psychoactive medicines in individuals with autism in the Autism Society of North Carolina. *J Child Adolesc Psychopharmacol*. 2002;12:311-321.
16. Levy SE, Mandell DS, Merhar S, Ittenbach RF, Pinto-Martin JA. Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *J Dev Behav Pediatr*. 2003;24:418-423.
17. Nickel RE. Controversial therapies for young children with developmental disabilities. *Infants Young Child*. 1996;8:29-40.
18. Yussman SM, Ryan SA, Auringer P, Weitzman M. Visits to complementary and alternative medicine providers by children and adolescents in the United States. *Ambul Pediatr*. 2004;4:429-435.
19. Hildebrand DG. *Cost-Benefit Analysis of Lovaas Treatment for Autism and Autism Spectrum Disorder (ASD)*. Vancouver, British Columbia: Columbia Pacific Consulting; 1999.
20. Jacobson JW, Mulick JA, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behav Intervent*. 1998;13:201-226.
21. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol*. 1987;55:3-9.
22. McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioral treatment. *Am J Ment Retard*. 1993;97:359-372.
23. Walsh KK, Kastner T, Criscione T. Characteristics of hospitalizations for people with developmental disabilities: utilization, costs, and impact of care coordination. *Am J Ment Retard*. 1997;101:505-520.
24. Fujiura GT, Roccoforte JA, Braddock D. Costs of family care for adults with mental retardation and related developmental disabilities. *Am J Ment Retard*. 1994;99:250-261.
25. Järbrink K, Knapp M. The economic impact of autism in Britain. *Autism*. 2001;5:7-22.
26. Parrish T, Harr J, Wolman J, Anthony J, Merickel A, Esra P. *State Special Education Finance Systems, 1999-2000. Part II: Special Education Revenues and Expenditures*. Palo Alto, Calif: Center for Special Education Finance; 2004.
27. Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA*. 2003;289:49-55.
28. Bureau of Labor Statistics. *Occupational Outlook Handbook, 2004-05 Edition*. Washington, DC: US Dept of Labor; 2004.
29. Capo LC. Autism, employment, and the role of occupational therapy. *Work*. 2001;16:201-207.
30. Heal LW, McCaughrin WB, Tines JJ. Methodological nuances and pitfalls of benefit-cost analysis: a critique. *Res Dev Disabil*. 1989;10:201-212.
31. Keel JH, Mesibov GB, Woods AV. TEACCH-supported employment program. *J Autism Dev Disord*. 1997;27:3-9.
32. Mawhood L, Howlin P. The outcome of a supported employment scheme for high functioning adults with autism or Asperger syndrome. *Autism*. 1999;3:229-254.
33. Rusch FR, Conley RW, McCaughrin B. Benefit-cost analysis of supported employment in Illinois: a statewide evaluation. *Am J Ment Retard*. 1990;95:44-54.
34. Skoog GR, Ciecka JE. The Markov (increment-decrement) model of labor force activity: extended tables of central tendency, variation, and probability intervals. *J Legal Econ*. 2001;11:23-87.
35. Congressional Budget Office. The budget and economic outlook: an update. August 2003. <http://www.cbo.gov/showdoc.cfm?index=4493&sequence=3>. Accessed January 4, 2005.
36. US Department of Commerce. *Statistical Abstract of the United States*. Washington, DC: Bureau of the Census; 2004.
37. Board of Governors of the Federal Reserve System. Foreign Exchange Rates Historical Data Series H.10. <http://www.federalreserve.gov/releases/H10/hist/>. Accessed January 4, 2005.
38. Congressional Budget Office. CBO's projections of the labor force. September 2004. <http://www.cbo.gov/showdoc.cfm?index=5803&sequence=0>. Accessed January 4, 2005.
39. American Academy of Pediatrics. The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*. 2001;107:1221-1226.
40. Butter EM, Wynn J, Mulick JA. Early intervention critical to autism treatment. *Pediatr Ann*. 2003;32:677-684.
41. Population Division. *Annual Estimates of the Population by Sex and Five-Year Age Groups for the United States: April 1, 2000 to July 1, 2003*. Washington, DC: US Census Bureau; 2004. [www.census.gov/popest/national/asrh/NCEST2003/NC-EST2003-01.pdf](http://www.census.gov/popest/national/asrh/NCEST2003/NC-EST2003-01.pdf). Accessed January 4, 2005.
42. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord*. 2003;33:365-382.
43. Fombonne E. The life expectancy of children diagnosed with a pervasive developmental disorder. *J Autism Dev Disord*. 2003;33:361.
44. Gillberg C. Outcome in autism and autistic-like conditions. *J Am Acad Child Adolesc Psychiatry*. 1991;30:375-382.
45. Shavelle RM, Strauss D. Comparative mortality of persons with autism in California, 1980-1996. *J Insur Med*. 1998;30:220-225.
46. Shavelle RM, Strauss DJ, Pickett J. Causes of death in autism. *J Autism Dev Disord*. 2001;31:569-576.
47. Maltby J. The costs of autism: more than meets the eye. *Advocate*. 2000;33(6):12-16. <http://www.autisminfo.com/Advocate.pdf>. Accessed December 24, 2004.
48. Folstein SE, Rosen-Sheidley B. Genetics of autism: complex aetiology for a heterogeneous disorder. *Nat Rev Genet*. 2001;2:943-955.
49. Alemayehu B, Warner KE. The lifetime distribution of health care costs. *Health Serv Res*. 2004;39:627-642.
50. Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Arch Pediatr Adolesc Med*. 2006;160:825-830.
51. Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*. 2006;118:e1203-e1211 <http://pediatrics.aappublications.org/cgi/content/full/118/4/e1203>.





## State of South Carolina State Health Plan Autism Spectrum Disorder Benefit

Effective with the 2009 Plan Year, the State Health Plan began covering Applied Behavior Analysis (ABA) for children diagnosed with an Autism Spectrum Disorder. The Employee Insurance Program (EIP) asked APS Healthcare to develop guidelines for administering the new benefit. Just like other services covered by APS for behavioral health diagnoses, the new Autism Spectrum Disorder (ASD) benefit services must be pre-authorized as medically necessary by APS, and providers must be contracted with APS as in-network providers. Only ABA providers fully certified by the Behavior Analyst Certification Board will be part of the network and be able to file claims for ABA services. All reimbursements for ABA services will be made by APS directly to ABA providers.

Board Certified Behavior Analysts (BCBA's) contracted with APS must provide direct supervision to their staff, including Board Certified Associate Behavior Analysts and/or any non-certified ABA therapists. Direct supervision includes the observation and oversight of the delivery of "hands on" ABA therapy by behavioral therapy staff.

The new benefit became effective on **January 1, 2009**. Following is a summary of requirements for coverage under the new benefit:

### **Eligibility Requirements:**

- 1) Member must be covered by the State Health Plan and under sixteen (16) years of age with no pre-existing condition exclusions.
- 2) Member must be diagnosed by age eight (8) with Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder Not Otherwise Specified by a Physician or Certified Registered Nurse Practitioner.
- 3) Diagnosis by age 8 must be confirmed by the following diagnosis-specific tests/screening tools:
  - a. Autistic Disorder using one of the following:
    1. Checklist for Autism in Toddlers (CHAT); or
    2. Modified Checklist for Autism in Toddlers (M-CHAT); or
    3. Screening Tool for Autism in Two-Year Olds (STAT); or
    4. Social Communication Questionnaire (SCQ) (recommended for children four-years of age or older).
  - b. Asperger's Syndrome using one of the following (recommended for school-age children):
    1. Autism Spectrum Screening Questionnaire (ASSQ); or
    2. Childhood Asperger Syndrome Test (CAST); or
    3. Krug Asperger's Disorder Index (KADI).
  - c. Pervasive Development Disorder, NOS using the following:
    1. One of the previously mentioned tools to rule out Autism and Asperger's; and
    2. DSM-IV Diagnostic Criteria/Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).
- 4) Member must be evaluated by an appropriate diagnostician to rule out the following as a sole explanation for symptoms of Autism Spectrum Disorder:
  - a. Neurological Disorder (must be by an MD),
  - b. Lead Poisoning (must be by an MD),
  - c. Primary Speech Disorder, and
  - d. Primary Hearing Disorder.
- 5) Member must be evaluated by a licensed Psychologist within the last 6 months for current validation of the ASD Diagnosis, using:
  - a. Autism Diagnostic Observation Schedule (ADOS); or
  - b. Autism Diagnostic Interview (ADI-R); or
  - c. Childhood Autism Rating Scale (CARS); or
  - d. A DSM-IV Diagnostic Criteria which validates one of the three ASD diagnoses.

### **Medical Necessity Authorization:**

**Medical necessity authorizations for services to be covered under the State Health Plan ABA benefit must be requested by ABA providers contracted with APS.** Before providers initiate the authorization procedure, they may call APS to confirm that the member is in fact covered by the State Health Plan. (Providers will want to make sure the member is not covered under the other State Employee Plans, which are HMO's BlueChoice and CIGNA.) Providers may also obtain information on coverage specifics from APS, such as member's deductible and benefit plan. Most members have a "Standard Plan" with yearly deductible of \$350 and reimbursement at 80% of contracted network fees, up to an out-of-pocket maximum of \$2000. After the out-of-pocket maximum is reached, reimbursement is 100% of network fees through the end of the year. A small number of members have the "Savings Plan" (identified on their ID card) which has a deductible of \$3000.

APS will advise the provider of authorization details, and letters will be sent to the provider and to the member/parents. All services under this benefit must be rendered on or after January 1, 2009.

All documentation of eligibility requirements must be submitted by the ABA provider to APS for review for authorization. The first authorization will be for an initial assessment by the ABA provider for the purpose of development of the ABA Treatment Plan. After the initial assessment takes place and the ABA Treatment Plan is finalized, the ABA provider will request authorization from APS for parent/primary caregiver training and for recommended ABA therapy in six month increments.

Contracted providers will file claims to APS for ABA services, and reimbursement will be made directly to ABA providers in accordance with pre-authorization(s). Reimbursement to ABA providers will be at contracted network fees, minus deductibles and coinsurance. ABA providers may ask for payment of patient liability (deductible and 20% co-insurance) at the time of service. APS reimbursement will be limited to \$50,000 for total ABA services per member per year, in accordance with medical necessity authorizations.

### **Medical Necessity Criteria:**

- 1) In order for services to be considered medically necessary they must:
  - a. Be for the purpose of diagnosis or assessment or treatment;
  - b. Be identified as part of a written Treatment Plan;
  - c. Include therapeutic goals which address cognition, behavior, communication, or social interaction skills;
  - d. Be directed by a provider credentialed by and contracted with APS Healthcare;
  - e. Meet all of the following:
    1. Be able to be coordinated with the member's Individualized Educational Program (IEP) if applicable;
    2. Have a specific plan for generalization to the member's home environment;
    3. Target observable, recordable, and measurable behaviors;
  - f. Be implemented by trained behavioral staff.
- 2) In order for previously authorized services to be considered medically necessary on an ongoing basis they must:
  - a. Demonstrate documented improvement over baseline and most recent measurement of targeted behaviors; and
  - b. Begin being provided within sixty (60) days of being authorized; and
  - c. Be provided with at least sixty percent (60%) of the frequency indicated in the written Treatment Plan; and
  - d. Demonstrate that the parents/primary caregivers have been trained in all interventions identified in the written Treatment Plan, and actively involved in the member's Treatment Plan as evidenced by attendance at all team meetings and being present at scheduled therapy sessions to the extent recommended by the BCBA provider. The written Treatment Plan must include a section outlining a plan for parental/primary caregiver participation.

Questions may be directed to State of South Carolina APS Customer Service at 800-221-8699.

Revised 1/06/09





**EXHIBIT 1**  
**FEE SCHEDULE – Autism Spectrum Disorder Program**  
**Under Utilization Management Products (South Carolina State Health Plan)**

**I. FEES**

ABA is a covered benefit when provided and directed by a credentialed and contracted APS provider. Services eligible for reimbursement include periodic evaluation of the member, development of a written treatment plan, oversight of the written treatment plan, direct supervision, training of parents/primary caregivers to implement services in accordance with the treatment plan, and “hands on” or “line” therapy. ABA services provided by behavioral health staff under the direction of the authorized BCBA provider.

APS will not pay for “hands on” or “line” therapy ABA services when provided by family members or other individuals who are not APS authorized providers.

Services must be directed and provided by an APS authorized provider on an outpatient basis and rendered in the member’s natural environment. This includes services provided at home, at school unless educational in nature, or other locations suitable for the type of services being rendered.

Reimbursement for ABA services will be paid at a per diem rate to the APS provider that is directing the care. The per diem rate is inclusive for all ABA services including oversight, direct supervision, “hands on” or “line” therapy by behavioral staff, parent/caregiver training and periodic treatment plan review.

Reimbursement for ABA services will only be paid directly to an authorized BCBA provider. The BCBA provider is responsible for reimbursing all staff under their supervision.

Reimbursement for assessment for the purpose of development of the initial and annual treatment plan, and reimbursement for training are not included in the per diem rate and may be billed separately.

**II. DEFINITIONS**

In addition to the definitions set forth in the Agreement, the following definitions shall have the meaning ascribed hereto for the purposes of this Exhibit:

- 1.1 “Usual and Customary Billed Charges” means the reasonable and customary fees charged by Independent Provider which do not exceed the fees Independent Provider would charge any other person regardless of whether the person is a Covered Individual.
- 1.2 “Utilization Management Product” shall refer to Benefit Plans under which Affiliate Payor has contracted with APS solely for access to APS’s Utilization Review services and/or network of Participating Providers.

**III. REIMBURSEMENT RATE FOR UTILIZATION MANAGEMENT PRODUCTS**

Reimbursement for the initial contract period to Independent Provider for Covered Services rendered to Covered Individuals, will be paid in accordance with the terms of this Agreement and the applicable Utilization Management Product, at the fee schedule set forth below, or Independent Provider’s Usual and Customary Billed Charges, whichever is lower.

<u>RATE</u>	<u>CPT CODE</u>	<u>DESCRIPTION</u>
\$116	99345-initial evaluation	This is the hourly rate for the initial assessment for the purpose of development of the initial treatment plan. Service will be authorized and reimbursed by the hour, with eight (8) hour standard maximum. The number of hours filed will be reflected in the Days/Units field of the claim form, and must correspond to the hours authorized.

\$212	99347-initial training	This is the hourly rate for the initial parent/primary caregiver training. Service will be authorized and reimbursed by the hour, with eight (8) hour standard maximum. Exceptions for additional training will be granted on case-by-case basis. The number of hours filed will be reflected in the Days/Units field of the claim form, and must correspond to the hours authorized.
\$207	99343	This is the daily rate for ABA services rendered at more than six (6) but not more than eight (8) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
\$186	99342	This is the daily rate for ABA services rendered at more than five (5) but not more than six (6) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
\$165	99341	This is the daily rate for ABA services rendered at more than four (4) but not more than (5) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
\$144	99344	This is the daily rate for ABA services rendered at up to four (4) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.

CPT codes 99344, 99343, 99342 and 99341 represent four separate levels of care. At the time of authorization for each Covered Individual, the level of care (and corresponding CPT code) will be determined according to the number of treatment hours that are authorized. In order for claims to be reimbursable, they must be filed with the CPT code established at the time of authorization.

## II. COMPENSATION PER CLAIM

The Compensation Per Claim payable by APS to Independent Provider, subject to the terms of this Agreement, the applicable Benefit Plan and corresponding Coordination of Benefit terms, shall be equal to:

- A. The Reimbursement Rate for Utilization Management Products
- B. Minus any applicable Copayments, Coinsurance and/or Deductibles

Independent Provider agrees that Covered Individuals shall not be billed for amounts in excess of the Deductibles, Copayments, and/or Coinsurance provided for in Covered Individual's Benefit Plan.



## **CIGNA HEALTHCARE COVERAGE POSITION**

**Subject Autism Spectrum  
Disorders/Pervasive  
Developmental Disorders:  
Assessment and Treatment**

**Revised Date ..... 4/15/2007  
Original Effective Date ..... 4/15/2006  
Coverage Position Number ..... 0447**

### **Table of Contents**

Coverage Position.....	1
General Background .....	3
Coding/Billing Information .....	17
References .....	18

### **Hyperlink to Related Coverage Positions**

Chelation Therapy  
Cognitive Rehabilitation  
Complementary and Alternative Medicine  
Genetic Counseling  
Genetic Testing  
Hyperbaric Oxygen Therapy  
Magnetoencephalography (MEG)  
Neuropsychological Testing  
Nuclear Imaging including Single-Photon  
Emission Computed Tomography  
(SPECT)  
Nutritional Counseling  
Occupational Therapy  
Preimplantation Genetic Diagnosis  
Secretin Acetate (Secreflo™)  
Sensory and Auditory Integration Therapy—  
Facilitated Communication  
Speech Generating Devices  
Speech/ Language Therapy  
Vision Therapy/Orthoptics

### **INSTRUCTIONS FOR USE**

Coverage Positions are intended to supplement certain **standard** CIGNA HealthCare benefit plans. Please note, the terms of a participant's particular benefit plan document [Group Service Agreement (GSA), Evidence of Coverage, Certificate of Coverage, Summary Plan Description (SPD) or similar plan document] may differ significantly from the standard benefit plans upon which these Coverage Positions are based. For example, a participant's benefit plan document may contain a specific exclusion related to a topic addressed in a Coverage Position. In the event of a conflict, a participant's benefit plan document **always supercedes** the information in the Coverage Positions. In the absence of a controlling federal or state coverage mandate, benefits are ultimately determined by the terms of the applicable benefit plan document. Coverage determinations in each specific instance require consideration of 1) the terms of the applicable group benefit plan document in effect on the date of service; 2) any applicable laws/regulations; 3) any relevant collateral source materials including Coverage Positions and; 4) the specific facts of the particular situation. Coverage Positions relate exclusively to the administration of health benefit plans. Coverage Positions are not recommendations for treatment and should never be used as treatment guidelines. ©2007 CIGNA Health Corporation

### **Coverage Position**

Some CIGNA HealthCare benefit plans specifically exclude therapy for learning disabilities, developmental delays, autism, and mental retardation or for that which is not restorative in nature. Please refer to the applicable CIGNA HealthCare benefit plan document to determine terms and conditions of coverage. Coverage for treatment of autism spectrum disorders (ASD) may also be mandated by state and/or federal mandates.

Services provided by a psychiatrist, psychologist or other behavioral health professionals are subject to the provisions of the applicable behavioral health benefit.

**Assessment and treatment for comorbid behavioral health and/or medical diagnoses and associated symptoms and/or conditions may be covered under applicable CIGNA HealthCare medical and behavioral health benefit plans.**

**When not otherwise excluded, CIGNA HealthCare covers medically necessary services for the treatment of autism spectrum disorders (ASD) when the criteria of the Diagnostic and Statistical Manual of Mental Health Disorders, Fourth Edition, Text Revision (DSM-IV-TR) are met.**

**Please refer to the CIGNA HealthCare Coverage Positions on Speech/Language Therapy, Occupational Therapy and Physical Therapy for specific coverage criteria for these therapies.**

**Services that are considered primarily educational or training in nature or related to improving academic or work performance are not covered under most CIGNA HealthCare benefit plans. CIGNA HealthCare does not cover the following services for the assessment and/or treatment of ASD because they are primarily educational and training in nature (this list may not be all-inclusive):**

- education and achievement testing
- educational intervention (e.g., classroom environmental manipulation, academic skills training and parental training)

**CIGNA HealthCare does not cover the following procedures/services for the assessment and/or treatment of ASD because they are considered experimental, investigational or unproven for this indication (these lists may not be all-inclusive):**

**Assessment:**

- allergy testing (e.g., food allergies for gluten, casein, candida, molds)
- celiac antibodies testing
- erythrocyte glutathione peroxidase studies
- event-related potentials (i.e., evoked potential studies)
- hair analysis
- immunologic or neurochemical abnormalities testing
- intestinal permeability studies
- magnetoencephalography (MEG)
- micronutrient testing (e.g., vitamin level)
- mitochondrial disorders testing (e.g., lactate and pyruvate)
- neuropsychological testing
- stool analysis
- thyroid function testing
- urinary peptides testing

**Treatment:**

- auditory integration therapy
- augmentative communication devices
- chelation therapy
- cognitive behavioral therapy
- cognitive rehabilitation
- craniosacral therapy
- dietary and nutritional interventions (e.g., elimination diets, vitamins)
- facilitated communication
- hyperbaric oxygen therapy
- intensive intervention programs for autism (e.g., Lovaas therapy, applied behavior analysis [ABA])
- immune globulin therapy

**Insurance Coverage for Pervasive Developmental Disorders**

This Bulletin is directed to all insurance companies that issue accident and sickness insurance policies as defined in IC 27-8-14.2-1 and to health maintenance organizations (HMOs) as defined in IC 27-13-1-19. Coverage for Pervasive Developmental Disorders (PDD) is a very complex issue. In 2001, the Indiana General Assembly passed P.L. 148-2001 adding IC 27-8-14.2 and IC 27-13-7-14.7. These provisions increased insurance coverage for persons suffering with PDD from what was available in the insurance market at that time. As is often the case, the bill that was passed contained compromises from the bills that were introduced, debated and amended. After a bill is passed and the statute is implemented it is not uncommon for interested persons to continue to dispute the meaning of the final language. The Department of Insurance is charged with implementing the provisions of Title 27. The Department must implement the statutes as they are written, giving meaning to each word of the statute. This Bulletin is intended to provide guidance to insurers and to consumers on contract language and administration of claims for the treatment of PDD as required by IC 27-8-14.2 and IC 27-13-7-14.7.

IC 27-8-14.2-4 requires that a group accident and sickness insurance policy must provide coverage for the treatment of PDD of an insured. IC 27-8-14.2-5 requires insurers that issue individual policies of accident and sickness insurance to offer to provide coverage for the treatment of PDD. And, IC 27-13-7-14.7 requires an HMO that provides basic health care services to provide services for the treatment of PDD of an enrollee. Neither insurers nor HMOs can deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, or reissue or otherwise terminate coverage on an individual solely because the individual is diagnosed with PDD.

A written treatment plan for each individual with PDD must be developed and signed by the treating physician. The treatment plan should be submitted to the insurer or HMO as soon as possible after its development to facilitate the payment of claims. If a non-physician recommends the treatment plan, it must be approved and signed by the treating physician. The Department of Insurance recognizes the insurer's or HMO's right to review the services prescribed under the treatment plan as to medical necessity. The insurer or HMO shall consult with the treating physician in its consideration of the treatment plan. Any challenge to medical necessity will be viewed as reasonable only if the review is by a specialist in the treatment of PDD. A specialist includes a clinical employee such as a medical director or PhD clinical administrator, provider or consultant of the insurer or HMO, and has specialized and current knowledge of PDD. Any challenge to medical necessity will be treated the same as any other grievance, following the grievance and appeals process as defined in IC 27-8-28, IC 27-8-29, IC 27-13-10, and IC 27-13-10.1.

The treatment plan must include all elements necessary for the insurer or HMO to appropriately pay claims. These elements include but are not limited to: a diagnosis, proposed treatment by type(s), frequency and duration of treatment(s), the anticipated outcomes stated as goals, the frequency by which the treatment plan will be updated, and the treating physician's signature. The insurer must provide, in writing, its determination regarding coverage for the services and supplies prescribed by the treatment plan within thirty (30) days of the insurer or HMO receiving the treatment plan. The insurer or HMO shall provide specific contact information for provider or member questions and shall facilitate filing of claims. An insurer or HMO that fails to provide its determination on the treatment plan within 30 days may be subject to enforcement action under IC 27-4-1-4.5.

Recognizing that PDD is a neurological condition, services will be provided without interruption, as long as those services are consistent with the treatment plan and with medical necessity decisions. Service exclusions contained in the insurance policy or HMO contract that are inconsistent with the treatment plan will be considered invalid as to PDD. However, coverage of services may be subject to other general exclusions and limitations of the contract or benefit plan, such as coordination of benefits, participating provider requirements, services provided by family or household members, eligibility, appeals processes, and carved out services (e.g. if the employer elects not to provide pharmacy coverage for any employees). IC 27-8-14.2-4(b), IC 27-8-14.2-5(b) and IC 27-13-7-14.7(c) and (e) state that the coverage or services that must be offered "may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally" under the accident and sickness policy or contract with the health maintenance organization. This provision allows the insurer or HMO to apply dollar limits, deductibles, co-payments and coinsurance as long as the application is consistent with coverage for physical illness generally. The Department considers dollar limits and visit limits to be synonymous for the purposes of this bulletin.

It is the Department's position that behavioral therapies such as Applied Behavioral Analysis Services may not be subject to limitations that apply to therapies such as physical, occupational or speech therapy. Further, Indiana does not currently have a licensing requirement for persons who perform Applied Behavioral Analysis Services. It is, therefore, inappropriate at this time for an insurer or HMO to deny a claim based upon the fact that the provider of Applied Behavioral Analysis Services does not hold a license.

The insurer shall have the right to request an updated treatment plan not more than once every six (6) months from the treating physician to review medical necessity, unless the insurer or HMO and the provider agree that a more frequent review is necessary due to emerging clinical circumstances. The cost of obtaining an updated treatment plan at the request of the insurer or HMO shall be borne by the insurer or HMO. This review does not alter the requirements and rights described in IC 27-8-29, IC 27-13-10 and IC 27-13-10.1.

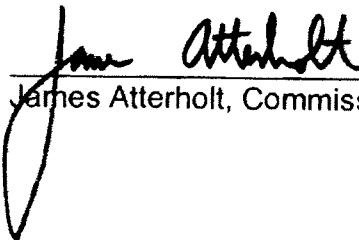
It is important for consumers to review their insurance coverage. For persons covered by individual policies, insurers are required to provide the insured with a copy of their insurance contract. For persons covered by group insurance policies or HMO contracts, the insurer or HMO is required to provide a copy of the certificate or evidence of coverage. While the insurer is not required to provide each covered person with a copy of the group insurance contract it should be made available if requested.

The insurance policies and HMO contracts affected by this Bulletin are required to be filed and approved by the Department. As guidance to the companies the Department approves the following language in its entirety:

1. Pervasive Development Disorder means a neurological condition, including but not limited to Asperger's syndrome and autism, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.
2. Coverage for services will be provided as prescribed by the insured's treating physician in accordance with a treatment plan.
3. Any exclusion within the policy, certificate or contract that is inconsistent with the treatment plan does not apply.
4. The benefits for Pervasive Developmental Disorder will not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy, certificate or HMO contract.

Any form in conflict with this Bulletin should be revised and filed with the Department. Policies, certificates, contracts, endorsements, or riders already approved for use may be used until the employer contract is amended, renewed, or terminated. However, the Department requires effective with the date of this Bulletin any insurer or HMO that is interpreting its policies more restrictively than the standards of this Bulletin shall adjudicate claims consistent with the provisions of the Bulletin. The Consumer Protection Unit of the Department encourages individuals to contact the Department with any concerns over the payment of claims. Each complaint will be reviewed individually for compliance with all applicable statutes.

INDIANA DEPARTMENT OF INSURANCE

  
James Atterholt, Commissioner

